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Patient, Partner and Physician

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<b>13. ABSTRACT (Maximum 200 Words)</b>  "Treatment Decisions in Localized Prostate Cancer: Patient, Partner and Physician," is a project that used a cross-sectional survey to explore the role of the patient, partner and physician in decisions about treatment of localized prostate cancer. The rationale for this study was based upon the significant uncertainty about the optimal treatment for localized prostate cancer and the need to include patients and partners in the decision making process. The study examined the effect of preferences and perceived preferences among patients, partners and physicians on treatment decisions, decision satisfaction and decision process. In the first six months of the project, survey instruments were developed, pilot tested and refined. Data collection began in November 2000 and terminated in October 2003 after data was collected from 233 patients, 132 spouses and 14 urologists (who saw 184 of the study patients). Although data analysis continues, numerous interesting results have been found to date, including poor knowledge of the common treatment options among patients, the impact of various decision factors on the choice of surgery, urologists misjudging their patients concerns and preferences, a strong influence of urologists' treatment recommendations on treatment choices, and an important role of the patient's spouse in the treatment decision. Many of these results have been presented at academic meetings and are in the process of being submitted for publication.				
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## **Introduction**

"Treatment Decisions in Localized Prostate Cancer: Patient, Partner and Physician," is a project that aims to develop and refine an innovative new model of prostate cancer decision making, that will form the foundation of a research and clinical program to understand, support and improve decision making in prostate cancer. We use a cross-sectional survey of patients, their spouses and their physicians to explore the role of the patient, partner and physician in treatment decisions, and to examine the effect of preferences, perceived preferences, and actual preferences on treatment decisions, decision satisfaction and decision process. By characterizing the role of the partner and the presence of significant misperceptions in the triad, and explicating the process of decision making under conditions of routine care, results of this project will serve as a basis for launching a research program in prostate cancer decision making. The guiding assumption of this work is that facilitation of communication and identification and resolution of misperceptions in the patient-partner-physician triad will improve patient satisfaction in decision making concerning localized prostate cancer.

## Body

### Task 1: Focus group discussions

In order to guide the development of the study survey instruments, we conducted 2 focus groups of men who had been newly diagnosed with prostate cancer to learn about their experiences of being diagnosed and making a treatment decision. This task has been completed and was reported in our 2001 Annual Report. These focus groups were held following the bimonthly prostatectomy clinic (a session for prostate cancer patients to learn what to expect with their upcoming surgery to remove their prostate) at the University of Pennsylvania. Discussion was guided towards the process men went through for being diagnosed with prostate cancer and learning about their treatment options, the information men received and sought from various sources about their diagnosis and treatment options, what factors influenced their treatment decision, including the impact of their interactions with their urologist and spouse on their decision. In addition to providing insight into these issues, focus group participants also guided us in understanding the ways in which the decision making process was stressful for them.

### Task 2: Development of Survey Instruments

In early discussions about the study, we decided to switch the study instrument from phone interviews to mailed surveys. Our reasoning for this change was the expectation of a greater response rate and more honest responses to a survey than to a phone interview.

In addition to the information gathered in Task 1, numerous steps were taken to collect information for developing the survey instruments for this study. We gathered information from an extensive literature review of decision making about prostate cancer and numerous discussions with experts in the field as well as the urologists and nurses who treat the patients at our study sites. With this information, the study team discussed the key elements to include in the survey instruments and preliminary surveys were developed to gather additional information from prostate cancer patients for use in the development of the final survey. The purpose of this preliminary survey was to learn about the process from diagnosis to treatment from the patient's perspective.

From this small-scale preliminary study (involving 5 prostate cancer patients), we learned about the steps of the process the men underwent. All of the men were first told of their treatment options by the urologist who did their biopsy and they were told of these options at the

same appointment during which they learned their biopsy results. Four of the 5 men had a spouse or another close family member present when they learned about their treatment options. Two of the 5 reported that their urologist recommended that they get a radical prostatectomy, and 3 of the men report speaking to a radiation oncologist before making their treatment decision. Of the 3 men who spoke to a radiation oncologist, 1 reported that his urologist recommended doing so. Three of the 5 men reported first thinking seriously about their treatment options upon learning of their positive diagnosis of prostate cancer. The fourth man first thought seriously about his options when he went for his prostate biopsy (the diagnostic test for prostate cancer) and for the fifth, it was some time after he received his results. Two of the 5 men reported making their treatment decision on their own, and 3 reported making the decision with their spouse. Each of the men also described what they did to gather information about treatment options before making their decision.

We consolidated all of the information we gathered in the steps described above to write preliminary patient, partner and physician surveys. These preliminary surveys were sent to prostate cancer patients and their spouses for feedback and suggested revisions. Participants were asked to note any omissions from the survey and any questions that they found confusing. Before and after comments were incorporated into the survey drafts, numerous drafts of the surveys were critically reviewed by each investigator on the grant and by other individuals who have expertise in research and survey design. These revisions required numerous project group meetings. A final patient survey, partner survey, and doctor survey has now been developed (Appendix A, B and C).

Task 2 has been completed, as we reported in our 2001 Annual Report.

### Task 3: Preparation of Interim Reports and Manuscripts

The final report is provided here. We are preparing manuscripts and have presented data from the study at the annual meeting of the Society for Medical Decision Making and the University of Pennsylvania Cancer Center Annual Scientific Symposium and Retreat. The abstracts are included below, as are descriptions of the manuscripts in preparation. These manuscripts include the results from the focus groups, although we have chosen not to try to publish the focus group findings on their own because of their limited number and difficulties in publishing focus group studies in major journals.

#### Task 4: Cross-sectional survey

##### *Development of data management system*

A unique data management system was developed because of the need to maintain complete confidentiality and anonymity of respondents, in keeping with DoD and University of Pennsylvania IRB requirements to protect respondent privacy, along with the need to maintain respondent name, address and phone numbers in order to facilitate interview rescheduling and follow-up.

First, a tracking database was established to record not only respondent name, address, phone number, but also when they should be contacted for consent and if they consent, when their survey should be sent to them. This information was kept in a password-protected MS Access file on a locked, password-protected computer in the project manager's office. This file was by nature and application entirely separate from the data file used for the survey responses.

Each respondent was assigned a unique identity code to distinguish his raw data from all other respondents' data. This code stood in lieu of personally identifiable information within the raw data databases; at no time were names, birthdates, addresses, phone numbers, or any other potentially personally identifying information stored with data from this project. Names and phone numbers were taken solely for purposes of contacting patients to obtain consent and to remind them to return their survey. Unique identifying codes were not linked to personally identifying information in the tracking database.

System backups were done on a weekly basis. Hard copies of all coding dictionaries were maintained and stored by the project manager and the research coordinator. Raw data were kept in a locked filing cabinet on a locked floor in our research facility which itself is locked and accessible only to authorized staff. Only members of the research team, the University of Pennsylvania IRB Human Subjects Committee (in accordance with University IRB requirements for research involving human subjects) and the grantor (the Department of Defense) have access to this raw data.

##### *Identification and recruitment of subjects*

The development of a subject identification and recruitment system involved several steps. Through numerous project meetings and extensive discussions with the physician and nurse providers of the prostate cancer patients in our sample, a system for identifying and recruiting each newly diagnosed localized prostate cancer patient was developed. At each

hospital in our sample, we learned about the process that patients undergo from the point of learning their prostate cancer diagnosis to beginning treatment. With this information, we were able to develop a system at each hospital for identifying new prostate cancer patients, informing them of our study (and their option to decline participation), obtaining consent in an oral consent interview, and having the patient, the patient's spouse and physician complete their respective surveys.

#### Site 1: Veteran's Affairs Medical Center (VAMC)

At the VAMC, new prostate cancer patients were identified when they arrived for their appointment to learn their prostate biopsy results. At the end of the appointment, their physician handed them a letter from us informing them of the study and giving them a phone number to call if they would like to decline participation. At this point, the physician completed the study's physician survey that examines his/her interactions with that patient. One week later, we sent the patient and his spouse a letter and consent form for both the patient and the spouse's participation in the study. After allowing for sufficient time to pass for the consent forms to arrive in the mail, we called the patient to conduct an oral consent interview with him and his spouse. When the consent interview was complete, if the patient and/or his spouse have consented to participate, we mailed the patient and spouse a survey packet. If the surveys were not returned within 3 weeks, we place a follow-up call to gently remind the subjects to please return their surveys.

#### Site 2: Hospital of the University of Pennsylvania (HUP)

The patients of two physicians at HUP were included in this study.

Physician 1: The nurse coordinator maintained a list of names of patients with positive biopsy results. Patients were added to the list when they called the nurse coordinator and received news of their prostate cancer diagnosis. A letter informing the patients of our study and the phone number to call to decline participation was included in a packet of information (about prostate cancer and treatment options) sent to each patient. Shortly thereafter, we sent the patient and his spouse a letter and consent form for both the patient and the spouse's participation in the study. After allowing for sufficient time to pass for the consent forms to arrive in the mail, we called the patient to conduct an oral consent interview with him and his spouse. When the consent interview was complete, if the patient and/or his spouse have consented to participate, we mailed the patient and spouse a survey packet. If



the surveys were not returned within 3 weeks, we placed a follow-up call to gently remind the subjects to please return their surveys.

Physician 2: The protocol for this physician was identical to that for Physician 1, with two exceptions. (1) This physician's patients were identified when patients called in to schedule a bone scan appointment. All newly diagnosed prostate cancer patients receive a bone scan at this hospital site. (2) We mailed the patient the letter informing him of our study and giving them a phone number to call to decline participation, rather than the letter being included in a packet of information already sent to the patient.

The rest of the protocol was identical to that for physician 1.

This task is complete; we have terminated subject recruitment and data collection for the study.

#### *Enrolling subjects and data collection*

In November 2000, we began identifying consecutive patients and enrolling them in our study. We identified 199 patients from the Hospital of the University of Pennsylvania (HUP) and 342 patients from the Philadelphia Veterans' Affairs Medical Center (VA). Mailed surveys, rather than phone interviews were used to collect data from patients and partners.

At HUP, 43 patients were excluded: 3 because of mental disorders, 33 declined participation, and 7 could not be contacted by telephone. Of the 156 HUP patients from whom we obtained oral, witnessed consent to participation, 106 (68%) completed study questionnaires. Eighty-five of these 106 patients had spouses, and 79 (92%) of the spouses completed a spouse questionnaire.

At the VA, 135 patients were excluded: 33 because of mental disorders, 1 was deceased, 42 have declined participation, and 59 could not be contacted by telephone. Of the 207 VA patients from whom we obtained oral, witnessed consent to participation, 127 (61%) completed study questionnaires. Seventy-one of these 123 patients have spouses, and 53 (75%) of the spouses completed a spouse questionnaire.

We have completed subject recruitment and data collection for the study and have data from a total of 233 patients (127 + 106), 132 spouses, and surveys from 14 urologists on 184 patients.

### *Physician completion of questionnaire*

After several meetings with participating physicians, a system was developed to facilitate physician completion of the study questionnaire among VA physicians only. After discussing the diagnosis and treatment options with each study patient, physicians completed a brief questionnaire about that patient.

We have completed data collection from the physicians. The 14 physicians at the VA who treated urology patients over the study period have completed questionnaires about 184 of their patients. Surveys were completed from both the physician and the patient from 68 physician-patient pairs.

### *Data entry and quality control measures*

Data were entered into the two databases described above. All entered data was checked against hard copies of patient information and surveys. Any detected errors were corrected. Data were backed up on a zip disk weekly with a new file name. This way, should a database become corrupted, a recent file version was available and could be easily updated with the most recent information. The data were (and are) also kept on a password protected computer.

We have completed data entry and data cleaning for the study.

### Task 5: Interim Data Quality Assessment (descriptive statistics)

Descriptive statistics were generated on an ongoing basis as data collection continued to ensure data quality. Data quality was also checked when the data are analyzed for presentations at academic meetings. See abstracts below for results from these analyses.

### **Key Research Accomplishments**

- Completion of data collection from newly diagnosed prostate cancer patients, their physicians and spouses
- Completion of data entry
- Data analysis
  - Comparison of urologists' perceptions of their patients' values and preferences to patients true values and preferences
  - Comparison of urologists' and patients' perception of the chance of cure with each of the common treatment options
  - Description of patients' treatment choice and the decision factors that influence these choices
  - The role of the urologists' recommendation on the treatment decision
  - Description of the process patients go through to gather information and make a treatment decision
  - Patients' knowledge of the common prostate cancer treatment options
    - Comparison of decision conflict and satisfaction according to treatment choice
    - Description of patient-spouse interaction about prostate cancer treatment decision
    - Comparison of patients' and spouse's perception of patients' values and preferences for treatment AND of spouse's values and preferences for treatment
  - Analyses of patient and spouse data are ongoing.
- Presentation of results at professional meetings
- Manuscripts in preparation:
  1. "Gaps between Patients and Physicians in Decision Making about Localized Prostate Cancer Treatment"
  2. "The Role of the Spouse in Decisions about Localized Prostate Cancer Treatment"
  3. "Racial Differences in Decisions about Treatment of Localized Prostate Cancer"
- Research findings:
  - Many patients gather information about their treatment options from various sources aside from their urologist, such as their primary care doctor, a radiation oncologist, the world wide web, medical books, and friends. Yet, after this information gathering process, a significant number of patients do not know of common prostate cancer

treatment options, even after having made their treatment decision (see abstract in Appendix D)

- Urologists misjudge their patients' concerns: Urologists judged their respective patients to be less concerned about impotence, incontinence and chance of cure than the patient rated himself to be, but some of these differences did not reach statistical significance (impotence:  $p=.08$ , incontinence:  $p=.10$ , chance of cure:  $p<.0001$ ). There was no difference in judgments of the patients' concern about risks of anesthesia.
- Urologists underestimate their respective patients' general desire for medical information and desire for information from the urologist about the diagnosis and treatment options relative to the patient's report of his information preferences ( $p=.0005$  and  $p=.01$  respectively).
- The majority of subjects reported that longevity, feeling certain the cancer was gone, avoiding impotence, the track record of the treatment, their spouse's opinion, their urologist's opinion, avoiding incontinence, how quickly the treatment works, their primary care doctor's opinion, keeping their body intact, recovery time from treatment and avoiding losing their identity as a man were very or extremely important to their treatment decision. Longevity, feeling certain the cancer was gone and impotence were rated as very or extremely important significantly more often in men choosing surgery ( $p<.04$  for those comparisons). Keeping one's body intact and avoiding losing identity as a man were rated as very or extremely important significantly more often in men choosing a nonsurgical treatment than in men choosing surgery (see abstract in Appendix D)
- Most patients want their urologist to make a treatment recommendation and most patients chose the treatment that their urologist recommended (see abstract in Appendix D)
- In their responses to items expressing their conflict and satisfaction about their prostate cancer treatment decision, subjects who chose surgery reported more satisfaction and less decision conflict than subjects who chose a nonsurgical treatment. Specifically, surgical patients more strongly agreed that they had made an informed choice ( $p=.02$ ), that their decision shows what is important for them ( $p=.08$ ), that they expect to stick with their decision ( $p=.07$ ), that they had the right amount of support from others in making this decision ( $p=.02$ ) and that they are satisfied with their decision ( $p=.02$ ).
- Patients' judgments of the likelihood of treatments curing their prostate cancer represent a misunderstanding relative to the gold standard of their urologists' judgments. Patients

rated surgery, radiation therapy and seed implants as less likely to cure than did urologists ( $p=.075$ ,  $p=.058$ ,  $p=.003$  respectively), and rated hormone therapy and watchful waiting as more likely to cure than did urologists ( $p<.0001$ ). There was not a significant difference between the urologists and patients in their rating of the chance of cure from watchful waiting, although patients rated watchful waiting as slightly more likely to cure.

- What was the role of the spouse in their husband, the patient's, treatment decision? For 49% of the patients with a spouse, the spouse was present during the discussion with the urologist about treatment options. Patients wanted their spouse's opinion to factor into the treatment decision slightly (but nonsignificantly) more than the spouse wanted her opinion to factor in ( $p=.08$ ), however, the spouse wanted to discuss the treatment options and decision more than her husband, the patient, did ( $p<.0001$ ). Spouses and patients disagreed on how the spouse deals with the prostate cancer diagnosis and treatment decision. The spouse reported doing each of the following more frequently than her husband, the patient, said that the spouse does: tries to persuade patient to follow doctor's instructions ( $p=.08$ ), tries to hide her worries about the patient ( $p=.0006$ ), tries to act as if nothing is the matter ( $p<.0001$ ), and gives in when the patient makes an issue of something ( $p=.0002$ ).
- Patients and their spouses misjudged each other's values and concerns. Spouse's underestimated the patient's concern about chance of cure ( $p<.0001$ ) and incontinence ( $p=.048$ ), and overestimated the patient's concern about risks of anesthesia ( $p=.021$ ). There was no difference in their judgment of the patient's concern about impotence. Patients overestimated his spouse's concern about incontinence ( $p=.0015$ ) and chance of cure ( $p<.0001$ ) and there was no difference in their judgment of the spouse's concern about impotence or risks of anesthesia.

## Reportable Outcomes

- Three abstracts which were presented at the University of Pennsylvania Cancer Center Annual Scientific Symposium and Retreat, March 2002 which have been updated with the most recent data analyses (Appendix D)

Gurmankin AD, Kaufman A, Ubel PA, Coyne JC, Malkowicz SB, & Armstrong K. Information-gathering process and knowledge of treatment options in men making prostate cancer treatment decisions. Poster presented at The Eunice and Irving Leopold Annual Scientific Symposium and Retreat. University of Pennsylvania Cancer Center, Philadelphia PA, March 2002

Gurmankin AD, Kaufman A, Ubel PA, Coyne JC, Malkowicz SB, & Armstrong K. The role of urologists' recommendations in treatment decisions of men with newly diagnosed prostate cancer. Poster presented at The Eunice and Irving Leopold Annual Scientific Symposium and Retreat. University of Pennsylvania Cancer Center, Philadelphia PA, March 2002

- Talk given at Society for Medical Decision Making, Baltimore MD, October 2002 (Appendix D)

Gurmankin AD, Kaufman A, Ubel PA, Coyne JC, Malkowicz SB, & Armstrong K. The clinical reality of prostate cancer treatment decisions: is shared decision making really necessary? Paper presented at annual meeting of the Society for Medical Decision Making, Baltimore MD, October 2002

## Conclusions

The past year has been productive and informative for this study. We have completed data collection including a total of 233 patients across both hospitals, and where applicable, their spouse and urologist. We have continued to conduct analyses of the data and have presented the data at relevant conferences, as described above. We are continuing to analyze the data and these analyses are contributing to additional abstracts for presentation at academic meetings and manuscripts in preparation for submission in the coming months.

Analyses to date have yielded interesting conclusions and areas in need of further research. First, even after having made a treatment decision, a substantial number of patients had not heard of some of the common treatment options that were available to them. Informed consent about medical procedures (e.g., prostatectomy) requires that patients be informed about their alternatives. In addition, relative to their urologists, patients misjudged the chance of cure from several of the common treatment options. These results call into question whether patients gave fully informed consent and may be attributable to urologists not providing their patients with sufficient information, as they underestimated their patients' desire for medical information.

Second, urologists' treatment recommendations strongly influenced their patients' treatment decisions, yet the urologists misjudged their patients' values and concerns about treatment. This may mean that patients accepted a treatment recommendation from their urologist that was inconsistent with their values and preferences for treatment.

Third, the study elucidated the factors that influence patients' choices of surgery versus radiation therapy for their localized prostate cancer and the factors that are most important to patients in their treatment decision. The results also revealed that patients who chose surgery were more satisfied and less conflicted about their decision even prior to undergoing treatment (which is when patients completed the survey).

Finally, the study revealed that there was disagreement between patients and their spouses on the desired role of the spouse in the treatment decision, the desired amount of discussion about the treatment decision, the spouse's response to the patient's situation, and in both the patient and the spouse's perception of each others' concerns about treatment side effects and chance of cure. These communication problems may lead patients to make treatment decisions based on a misunderstanding of what their spouse – whose opinion is very important to them – wants.

## **Appendix A: Patient survey**



**Instructions:**

**This questionnaire asks about your experiences with the diagnosis of prostate cancer and deciding on a treatment. Your answers will be strictly confidential. It is extremely important that you follow these guidelines when filling out this questionnaire:**

- 1. Please fill it out and return it to us AFTER you have made your prostate cancer treatment decision but BEFORE you have begun ANY treatment for prostate cancer (i.e. surgery, radiation, seed implants, etc).**
- 2. Please fill out this questionnaire without any communication between you and your partner. We are interested in YOUR thoughts, even on the questions that ask about your partner. So please do not get any information or input from your partner while filling out the questionnaire.**
- 3. Please answer every question to the best of your ability, even if you are unsure of your response.**

**If you have any questions, please feel free to contact Marie Offt at 215 573-9718.  
Thank you in advance for your participation.**

Date you are filling out this questionnaire: \_\_\_\_/\_\_\_\_/\_\_\_\_

Who is your urologist? \_\_\_\_\_ (Your doctor will never see your responses)

**Part A. The first set of questions asks about your treatment decision.**

- 1) Which of the following possible treatments for prostate cancer have you heard of? (*check all that you have heard of*)
  - ☐ Surgery (Radical prostatectomy- procedure where they remove the prostate)
  - ☐ Radiation therapy
  - ☐ Seed implants (Brachytherapy)
  - ☐ Hormone therapy
  - ☐ Watchful waiting (No treatment, but getting regular blood tests to check on the status of the cancer)
- 2) Which treatment have you chosen? (*check all that apply*)

<input type="checkbox"/> Surgery	<input type="checkbox"/> Radiation therapy	<input type="checkbox"/> Watchful waiting
<input type="checkbox"/> Seed implants	<input type="checkbox"/> Hormone therapy	<input type="checkbox"/> Other (Please explain):

3) What have you done to get information about your treatment options (*check all that apply*)

- ☐ Speak to my doctor  
Which doctor(s)? ☐ Urologist ☐ Primary care doctor ☐ Other
- ☐ Speak to friend/acquaintance who is a doctor
- ☐ Speak to prostate cancer survivors
- ☐ Get information on the internet
- ☐ Get information in medical books/journals
- ☐ Other (Please explain below where else you got information):

Based on the information you have, what do you think your chance of impotence is? (Please give a number between 0% and 100%). \_\_\_\_\_

Based on the information you have, please rate what you think your chance of impotence is (*circle one number*):

- |                      |                    |                    |                |                     |
|----------------------|--------------------|--------------------|----------------|---------------------|
| 1                    | 2                  | 3                  | 4              | 5                   |
| Not at all<br>likely | Slightly<br>likely | Somewhat<br>likely | Very<br>likely | Extremely<br>likely |

Based on the information you have, what do you think your chance of incontinence is? (Please give a number between 0% and 100%). \_\_\_\_\_

Based on the information you have, please rate what you think your chance of incontinence is (*circle one number*):

- |                      |                    |                    |                |                     |
|----------------------|--------------------|--------------------|----------------|---------------------|
| 1                    | 2                  | 3                  | 4              | 5                   |
| Not at all<br>likely | Slightly<br>likely | Somewhat<br>likely | Very<br>likely | Extremely<br>likely |

Based on the information you have, what do you think your chance of death is? (Please give a number between 0% and 100%). \_\_\_\_\_

Based on the information you have, please rate what you think your chance of death is (*circle one number*):

- |                      |                    |                    |                |                     |
|----------------------|--------------------|--------------------|----------------|---------------------|
| 1                    | 2                  | 3                  | 4              | 5                   |
| Not at all<br>likely | Slightly<br>likely | Somewhat<br>likely | Very<br>likely | Extremely<br>likely |

Based on the information you have, what do you think your chance of cure is? (Please give a number between 0% and 100%). \_\_\_\_\_

Based on the information you have, please rate what you think your chance of cure is (*circle one number*):

- |                      |                    |                    |                |                     |
|----------------------|--------------------|--------------------|----------------|---------------------|
| 1                    | 2                  | 3                  | 4              | 5                   |
| Not at all<br>likely | Slightly<br>likely | Somewhat<br>likely | Very<br>likely | Extremely<br>likely |

- 4) Approximately when did you make your final decision about what treatment you would get for your prostate cancer? This includes deciding on watchful waiting. (*We understand it may be difficult to remember the date, so please just give your best estimate*). \_\_\_\_\_ / \_\_\_\_\_ / \_\_\_\_\_

5) How important were each of the following things in making your decision:	Extremely important	Very important	Somewhat important	Slightly important	Not at all important
a) the possibility of impotence (inability to get or maintain an erection)	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
b) the possibility of incontinence (trouble controlling your urine)	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
c) the risks of anesthesia (the medicine given to patients to put them to sleep during surgery)	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
d) the need to feel certain that the cancer is completely gone	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
e) keeping my body intact					
f) avoiding losing my identity as a man					
g) the cost of the treatment					
h) the desire to live as long as possible					
i) the discomfort of the treatment					
j) the inconvenience of the time it takes to get the treatment	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
k) your urologist's opinion	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
l) your primary care doctor's opinion	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
m) your partner's opinion ( <i>leave blank if you don't have a partner</i> )	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
n) another family member's opinion (how are you related to this person?): _____	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
o) the opinion of a friend or acquaintance who has or has had prostate cancer	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
p) information from other sources (what sources):					
q) Other (please explain):	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
r) Other (please explain):	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>

--	--	--	--	--	--

- 6) Now please circle the letter beside the one factor listed **above in question 5** that was the **most important factor** in your treatment decision.

**Part B. The next questions ask about when you were first diagnosed with prostate cancer.**

- 1) Which doctor did you **first** speak to about whether you should get a biopsy to look for prostate cancer?
- ☐ My primary care doctor    ☐ A friend/acquaintance who is a doctor  
☐ A urologist    ☐ Other (Please explain):
- 2) Why did you have this conversation about getting a biopsy? (*Check all that apply*)
- ☐ I had an abnormal PSA test (blood test)  
☐ I had an abnormal rectal exam (the doctor felt something suspicious when he felt my prostate)  
☐ I had symptoms from my prostate (trouble passing urine, blood in urine, incontinence)  
☐ I was concerned about a history of prostate cancer in my family  
☐ Other (Please explain):
- 3) Which doctor did you **first** speak to about your treatment options for prostate cancer?
- ☐ My primary care doctor    ☐ A friend/acquaintance who is a doctor  
☐ A urologist    ☐ Other (please explain):
- 4) When did this conversation occur?
- ☐ during an appointment or conversation **before I got my biopsy results**  
☐ **during** the same appointment or conversation in which I **got my biopsy results**  
☐ during an appointment or conversation at some point **after I got my biopsy results**  
☐ Other (please explain):
- 5) Was your partner present during this conversation?
- ☐ Yes    ☐ No    ☐ I have no partner

If the first time you talked to a doctor about treatment options was NOT with a urologist:  
6)

- a) When was the main conversation you had with a urologist about your treatment options?
- ☐ during an appointment or conversation **before I got my biopsy results**
  - ☐ **during** the same appointment or conversation in which I **got my biopsy results**
  - ☐ during an appointment or conversation at some point **after I got my biopsy results**
  - ☐ Not applicable
  - ☐ Other (please explain):

b) Was your partner present during this conversation about treatment options with the urologist?

- ☐ Yes      ☐ No      ☐ I have no partner

**Part C. The next set of questions asks more about your conversation with your urologist about treatment options. If you have not yet spoken to your urologist about treatment options, please skip to Part D.**

1) Approximately what was the date of your conversation with your urologist about your treatment options (*please give your best estimate*) \_\_\_\_ / \_\_\_\_ / \_\_\_\_

2) About how much time did you spend talking with the urologist about your treatment options? (*please give your best estimate*) \_\_\_\_ minutes

3) Would you have preferred to spend more or less time talking with the urologist?  
(*Please circle a number below*)

1	2	3	4	5
Much less	A little less	Neither more nor less	A little less	Much more

4) Did the urologist →

- |   |                              |                             |
|---|------------------------------|-----------------------------|
| a) mention the option of getting surgery?           | <input type="checkbox"/> Yes | <input type="checkbox"/> No |
| b) mention the option of getting radiation therapy? | <input type="checkbox"/> Yes | <input type="checkbox"/> No |
| c) mention the option of getting seed implants?     | <input type="checkbox"/> Yes | <input type="checkbox"/> No |
| d) mention the option of getting hormone therapy?   | <input type="checkbox"/> Yes | <input type="checkbox"/> No |
| e) mention the option of watchful waiting?          | <input type="checkbox"/> Yes | <input type="checkbox"/> No |

5) Would you have preferred more or less information from the urologist? (*Please circle a number below*)

1	2	3	4	5
Much less	A little less	Neither more nor less	A little more	Much more

- 6) If you had any questions for the urologist, did you feel free to ask your questions?
- ☐ I did not have any questions
  - ☐ Yes
  - ☐ No → Why not?:

Did your urologist give you **information about each of the following** things using **numbers** (for example, "a 2% chance") or **words** (for example, "a very small chance")?

**Chance of impotence:**

- ☐ No numbers/only words
- ☐ Only numbers/no words
- ☐ Some numbers/some words
- ☐ I don't know

**Chance of incontinence:**

- ☐ No numbers/only words
- ☐ Only numbers/no words
- ☐ Some numbers/some words
- ☐ I don't know

**Chance of death:**

- ☐ No numbers/only words
- ☐ Only numbers/no words
- ☐ Some numbers/some words
- ☐ I don't know

**Chance of cure:**

- ☐ No numbers/only words
- ☐ Only numbers/no words
- ☐ Some numbers/some words
- ☐ I don't know

- 7) Did the urologist recommend a particular treatment to you? ☐ Yes ☐ No

*If yes →*

a) What was the urologist's treatment recommendation?

b) How strong was the urologist's recommendation? (*circle one number*)

- |                      |                    |                    |                |                     |
|----------------------|--------------------|--------------------|----------------|---------------------|
| 1                    | 2                  | 3                  | 4              | 5                   |
| Not at all<br>strong | Slightly<br>strong | Somewhat<br>strong | Very<br>strong | Extremely<br>strong |

- 8) Did you want the urologist to provide a recommendation? ☐ Yes ☐ No

Please explain:

- 9) Did the urologist suggest that you speak to a radiation oncologist? ☐ Yes ☐ No

- 10) Did you speak with a radiation oncologist? ☐ Yes ☐ No
- 11) Did you get a second opinion from another urologist? ☐ Yes ☐ No
- 12) Which of the following best describes how the decision about your prostate cancer treatment was made?
- ☐ My urologist made the final decision
  - ☐ My urologist made the final decision after seriously considering my opinion
  - ☐ My urologist and I shared responsibility for the final decision.
  - ☐ I made the final decision after seriously considering my urologist's opinion.
  - ☐ I made the final decision on the basis of the facts I learned from my urologist and elsewhere, without considering my doctor's opinion.

**Part D. The next questions ask about your thoughts about different treatments and side effects.**

1) How concerned are you about experiencing:	Extremely concerned	Very concerned	Somewhat concerned	Slightly concerned	Not at all concerned
a) Incontinence (trouble controlling your urine)	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
b) Impotence (trouble getting or maintaining an erection)	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
c) Risks of anesthesia (the medicine given to patients to put them to sleep during surgery)	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>

- 2) Which treatment do you think has the best chance of cure for you?
- ☐ Surgery                      ☐ Radiation therapy                      ☐ Hormone therapy  
☐ Watchful waiting   ☐ Seed implants                      ☐ I don't know  
☐ They all have the same chance of cure
- 3) Which treatment do you think has the best chance of avoiding side effects?
- ☐ Surgery                      ☐ Radiation therapy                      ☐ Hormone therapy  
☐ Watchful waiting   ☐ Seed implants                      ☐ I don't know  
☐ They all have the same chance of avoiding side effects

**Part E. Next we ask about what you think YOUR PARTNER thinks about different treatment options. We also ask about the discussions you two had about your options. *If you do not have a partner, skip to Part F.* Please remember to respond without input from your partner.**

1) How concerned do you think your partner is about you experiencing:	Extremely concerned	Very concerned	Somewhat concerned	Slightly concerned	Not at all concerned
a) incontinence (trouble controlling your urine)?	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
b) impotence (which is the inability to attain or maintain an erection)?	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
c) the risks of anesthesia (the medicine that they give to patients to put them to sleep during the surgery)?	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>

- 2) Which treatment do you think your partner thinks has the best chance of cure for you?
- ☐ Surgery                      ☐ Radiation therapy                      ☐ Hormone therapy  
☐ Watchful waiting   ☐ Seed implants  
☐ I don't know what my partner thinks  
☐ They all have the same chance of cure



- 3) Which treatment do you think your partner thinks has the best chance of avoiding side effects?
- ☐ Surgery      ☐ Radiation therapy      ☐ Hormone therapy
- ☐ Watchful waiting      ☐ Seed implants
- ☐ I don't know what my partner thinks
- ☐ They all have the same chance of avoiding side effects
- 4) If it had been up to your partner, which treatment do you think she would have chosen for you?
- ☐ Surgery      ☐ Radiation therapy      ☐ Hormone therapy
- ☐ Watchful waiting      ☐ Seed implants
- ☐ I don't know what my partner would have chosen
- ☐ Other (please explain):
- 5) How does your partner feel about the treatment that was chosen?
- ☐ Insisted that I get it      ☐ Opposed the decision
- ☐ Supported the decision      ☐ Insisted that I not get it
- ☐ I don't know how my partner feels
- ☐ Other (please explain):
- 6) How often did you and your partner discuss your treatment options? (*please circle a number below*)
- |       |        |              |             |            |
|-------|--------|--------------|-------------|------------|
| 1     | 2      | 3            | 4           | 5          |
| Never | Seldom | Now and then | Quite often | Very often |
- 7) Would you have preferred to discuss your treatment options more or less? (*please circle a number below*)
- |           |               |                       |               |           |
|-----------|---------------|-----------------------|---------------|-----------|
| 1         | 2             | 3                     | 4             | 5         |
| Much less | A little less | Neither more nor less | A little more | Much more |

***If you responded "never" to question 6, skip to question 11. Otherwise, continue to question 7.***

- 8) When you had these discussions about treatment options, who initiated them?
- ☐ Me      ☐ My partner      ☐ We both initiated some of the discussions.
- 9) How satisfied were you with those discussions? (*please circle a number below*)
- |                   |                       |                                    |                    |                |
|-------------------|-----------------------|------------------------------------|--------------------|----------------|
| 1                 | 2                     | 3                                  | 4                  | 5              |
| Very dissatisfied | Somewhat dissatisfied | Neither satisfied nor dissatisfied | Somewhat satisfied | Very satisfied |
- 10) How often did you and your partner get into a disagreement or conflict over the issue of which treatment to choose? (*please circle a number below*)

1                      2                      3                      4                      5  
 Never                      Seldom                      Now and then                      Quite often                      Very often

10) How strongly did you want your partner's opinion to be factored into your treatment decision? (circle a number below)

1                      2                      3                      4                      5  
 Not at all                      A little                      Somewhat                      Very                      Extremely

**The following statements focus on the way your partner deals with the fact that you have prostate cancer. Please indicate to what extent your partner does or does not act in the ways described.**

	Never	Seldom	Now and then	Quite often	Very often
11) My partner tries to discuss it with me openly	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
12) My partner asks me how I feel	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
13) When something bothers me, my partner tries to discuss the problem	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
14) My partner is full of understanding towards me	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
15) My partner makes me feel that I'm not alone in this	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
16) My partner tries to persuade me to follow the doctor's instructions	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
17) My partner tries to hide his or her worries about me	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
18) My partner tries to act as if nothing is the matter	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
19) My partner gives in when I make an issue of something	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
20) My partner just waves my worries aside	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
21) My partner does everything to prevent me from thinking about my disease	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
22) My partner can't endure me being concerned and acts as if she doesn't notice my worries	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
23) My partner takes over as much of my work as possible	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>

**Part F. This set of questions asks about your feelings of conflict over your decision. The statements below are things that some people say when they have just made a difficult decision. Thinking about your prostate cancer treatment decision, please check the box that best matches how much you agree with each statement.**

	<b>Strongly agree</b>	<b>Agree</b>	<b>Neither agree nor disagree</b>	<b>Disagree</b>	<b>Strongly disagree</b>
1) I feel I have made an informed choice	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
2) My decision shows what is most important for me.	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
3) I expect to stick to my decision.	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
4) I am satisfied with my decision.	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
5) This decision was hard for me to make	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
6) I was unsure what to do in this decision	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
7) It was clear what choice was best for me	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
8) I am aware of the choices I have to manage my prostate cancer	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
9) I feel I know the benefits of the treatments for prostate cancer.	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
10) I feel I know the risks and side effects of treatment for prostate cancer.	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
11) I need more advice and information about the choices.	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
12) I know how important the benefits of the treatment for prostate cancer are to me in this decision.	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
13) I felt pressure from others in making this decision.	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
14) I had the right amount of support from others in making this decision.	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>

**Part G. The next questions ask about your background.**

- 1) What is your age? \_\_\_\_\_ years
- 2) What is your race?  
☐ African-American      ☐ Caucasian      ☐ Hispanic  
☐ Asian-American      ☐ Other (please specify) \_\_\_\_\_
- 3) What level of education have you completed? (*Circle one number*)  
9 10 11 12      13 14 15 16      17 18 19 20 21+  
high school      college      graduate school
- 4) Have you had any of these conditions in the past 12 months?  
☐ high blood pressure      ☐ heart trouble  
☐ diabetes      ☐ emotional or mental illness  
☐ stroke      ☐ chronic bronchitis  
☐ asthma      ☐ arthritis or rheumatism  
☐ cancer (other than prostate)      ☐ epilepsy  
☐ chronic nervous trouble      ☐ tuberculosis  
☐ hernia or rupture      ☐ chronic liver problem  
☐ drinking problems or alcoholism      ☐ chronic gallbladder trouble  
☐ stomach ulcer or duodenal ulcer
- 5) Are you currently experiencing impotence? ☐ Yes      ☐ No
- 6) Are you currently experiencing incontinence? ☐ Yes      ☐ No
- 7) Do you currently have health insurance? ☐ Yes      ☐ No      ☐ Not sure
- If yes* ➤ please check the type of plan that best describes your current health insurance:  
☐ Fee-for-service plan where you can go to any doctor or hospital  
☐ HMO where your primary care doctor refers you to specialists  
☐ PPO where you can go to any doctor or hospital on a list without getting a referral  
☐ I don't know which type of plan I have

**Part H. This section asks about your relationship with your partner. *If you do not have a partner, skip to Part I.***

Most people have some disagreements in their relationships. Below is a series of issues. We'd like you to tell us of any disagreement experienced between you and your partner over each of these issues in a typical month (this past month may not have been typical for you, since you were just diagnosed with prostate cancer). So for each issue, please tell us if in a typical month, you have always agreed, almost always agreed, occasionally disagreed, frequently disagreed, almost always disagreed, or always disagreed.

	<b>In the past month, my spouse and I have</b>	<b>Always agreed</b>	<b>Almost always agreed</b>	<b>Occasionally agreed</b>	<b>Frequently disagreed</b>	<b>Almost always disagreed</b>	<b>Always disagreed</b>
1)	Religious matters	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
2)	Demonstration of affection	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
3)	Sex relations	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
4)	Conventionality (correct or proper behavior)	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
5)	Making major decisions	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
6)	Career decisions	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>

	<b>How often do you and your partner do the following things:</b>	<b>All the time</b>	<b>Most of the time</b>	<b>More often than not</b>	<b>Occasionally</b>	<b>Rarely</b>	<b>Never</b>
7)	discuss or consider divorce, separation, or terminating your relationship?	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
8)	regret that you married?	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
9)	quarrel?	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
10)	"get on each other's nerves?"	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>

		<b>Every day</b>	<b>Almost every day</b>	<b>Occasionally</b>	<b>Rarely</b>	<b>Never</b>
11)	How often do you and your spouse/partner engage in outside interests together?	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>

Below are some things that you and your spouse/partner might do. Please tell us how often you think they occur between you and your spouse/partner.

		More than once a day	Once a day	Once or twice a week	Once or twice a month	Less than once a month	Never
12)	Have a stimulating exchange of ideas	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
13)	Calmly discuss something	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
14)	Work together on a project	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>

8) How often does your partner go with you to your doctors' appointments?

1                      2                      3                      4                      5  
Never              Once in a while              Sometimes              Frequently              Always

9) How long have you and your partner been married or together? \_\_\_\_\_ years

**Part I. This last section asks about your quality of life.**

During the past four weeks how much of the time ...	All of the time	Most of the time	A good bit of the time	Some of the time	A little of the time	None of the time
1. Have you been concerned or worried about loss of muscle tone?	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
2. Did you have negative feelings about the way your body looks?	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
3. Did you avoid being seen without a shirt on?	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
4. Did you feel that your body was getting soft and flabby?	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
5. Were you concerned or worried about difficulty getting or keeping an erection?	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
6. Did you wish you could regain your sexual ability?	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
7. Did you feel frustrated about your sexual ability?	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
8. Did you feel despair over the loss of sexual ability?	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>

*Skip this part if you do not have a spouse*

How true or false has each of the following statements been for you during the past four weeks?	Definitely true	Mostly true	Neither true no false	Mostly false	Definitely false
---	--------------------	----------------	-----------------------------	-----------------	---------------------

9. I felt uncomfortable when my spouse or partner wanted to hug or kiss me.	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
10. I felt affectionate about my spouse or partner.	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
11. I felt that my spouse or partner was not satisfied with our sex life.	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
12. I felt that my spouse or partner may want to turn to others for affection.	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
13. My spouse or partner was worried about my cancer.	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
14. I worked hard to keep my spouse or partner from worrying about my health.	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
15. Since I've had cancer I feel that I have lost my ability to be aggressive.	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
16. I feel that I've lost part of my manhood.	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
17. I feel as if I'm going through a "change of life" like women do.	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
18. I feel that what I say is not taken very seriously by others.	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>

<b>During the past four weeks how much of the time ...</b>	<b>All of the time</b>	<b>Most of the time</b>	<b>A good bit of the time</b>	<b>Some of the time</b>	<b>A little of the time</b>	<b>None of the time</b>
19. Did you feel that you cancer kept you from being the friend you wanted to be?	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
20. Did you feel that other people don't really understand what it's like to have prostate cancer?	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
21. Did you feel that you were a bother to other people?	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
22. Did you worry about eventually becoming unable to take care of yourself?	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
23. Did you worry about your cancer, but keep it to yourself?	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
24. Did you feel that others who are close to you try to hide their true feelings about your cancer?	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
25. Did you feel that others think less of you because of your health problems?	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
26. Have you felt weak and small?	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
27. Have you worried about the cancer spreading?	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
28. Have you thought about your cancer?	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>

29. Have you worried about dying soon?	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
30. Have you been concerned about side-effects of your cancer treatment?	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
31. Have you felt that your cancer has given you a better outlook on your life?	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
32. Have you felt that coping with your cancer has made you a stronger person?	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
33. Have you wished that you could change your mind about the kind of treatment you chose for your prostate cancer?	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>



How true or false has each of the following statements been for you during the past four weeks?	Definitely true	Mostly true	Neither true nor false	Mostly false	Definitely false
34. I feel that I would be better off if I had chosen another treatment for prostate cancer.	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
35. It bothers me that other men with prostate cancer get treatment that is very different from what I will receive.	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>

**Thank you for your participation. Please mail the completed survey in the enclosed, stamped, addressed envelope.**

## **Appendix B: Partner survey**

**Instructions:**

This questionnaire asks about your experiences with your spouse or partner's diagnosis of prostate cancer and deciding on a treatment. Your answers will be kept strictly confidential. It is extremely important that you follow these guidelines when filling out this questionnaire:

1. Please fill it out and return it to us **AFTER** your partner's treatment decision has been made but **BEFORE** your partner has begun or undergone ANY treatment for prostate cancer (i.e. surgery, radiation, seed implants, etc).
2. Please fill out this questionnaire without any communication between you and your partner. We are interested in **YOUR** thoughts, even on the questions that ask about your partner. So please do not get any information or input from your spouse while filling out the questionnaire.
3. Please answer every question to the best of your ability, even if you are unsure of your response.

If you have any questions, please feel free to contact Marie Offt at 215-573-9718.  
Thank you in advance for your participation.

Date you are filling out this questionnaire: \_\_\_\_ / \_\_\_\_ / \_\_\_\_

- 1) Which of the following possible treatments for prostate cancer have you heard of (*check all that you have heard of*)?

- ☐ Surgery (Radical prostatectomy- procedure where they remove the prostate)
- ☐ Radiation therapy
- ☐ Seed implants (Brachytherapy)
- ☐ Hormone therapy
- ☐ Watchful waiting (No treatment, but getting regular blood tests to check on the status of the cancer)

Based on the information you have, what do you think your chance of impotence is? (Please give a number between 0% and 100%). \_\_\_\_\_

Based on the information you have, please rate what you think your chance of impotence is (*circle one number*):

- |                      |                    |                    |                |                     |
|----------------------|--------------------|--------------------|----------------|---------------------|
| 1                    | 2                  | 3                  | 4              | 5                   |
| Not at all<br>likely | Slightly<br>likely | Somewhat<br>likely | Very<br>likely | Extremely<br>likely |

Based on the information you have, what do you think your partner's chance of incontinence is? (Please give a number between 0% and 100%). \_\_\_\_\_

Based on the information you have, please rate what you think your partner's chance of incontinence is (*circle one number*):

1	2	3	4	5
Not at all likely	Slightly likely	Somewhat likely	Very likely	Extremely likely

Based on the information you have, what do you think your partner's chance of death is? (Please give a number between 0% and 100%). \_\_\_\_\_

Based on the information you have, please rate what you think your partner's chance of death is (*circle one number*):

1	2	3	4	5
Not at all likely	Slightly likely	Somewhat likely	Very likely	Extremely likely

Based on the information you have, what do you think your partner's chance of cure is? (Please give a number between 0% and 100%). \_\_\_\_\_

Based on the information you have, please rate what you think your partner's chance of cure is (*circle one number*):

1	2	3	4	5
Not at all likely	Slightly likely	Somewhat likely	Very likely	Extremely likely

**Questions 2-7 ask about YOUR thoughts about different prostate cancer treatments and their possible side effects**

2) How concerned are **you** about your partner experiencing incontinence (which is trouble controlling his urine)?

<input type="checkbox"/> Extremely concerned	<input type="checkbox"/> Very concerned	<input type="checkbox"/> Somewhat concerned
<input type="checkbox"/> Slightly concerned	<input type="checkbox"/> Not at all concerned	

3) How concerned are **you** about your partner experiencing impotence (which is the inability to attain or maintain an erection)?

<input type="checkbox"/> Extremely concerned	<input type="checkbox"/> Very concerned	<input type="checkbox"/> Somewhat concerned
<input type="checkbox"/> Slightly concerned	<input type="checkbox"/> Not at all concerned	

4) How concerned are **you** about your partner experiencing the risks of anesthesia (the medicine that they give to patients to put them to sleep during the surgery during which they remove the prostate)? Are you..

<input type="checkbox"/> Extremely concerned	<input type="checkbox"/> Very concerned	<input type="checkbox"/> Somewhat concerned
<input type="checkbox"/> Slightly concerned	<input type="checkbox"/> Not at all concerned	

- 5) Which treatment do **you** think has the best chance of cure for your spouse/partner?
- ☐ Surgery                      ☐ Radiation therapy                      ☐ Watchful waiting
- ☐ Seed implants                      ☐ They all have the same chance of cure
- 6) Which treatment do **you** think has the best chance of avoiding side effects?
- ☐ Surgery (Radical prostatectomy- procedure where they remove the prostate)
- ☐ Radiation therapy
- ☐ seed implants (Brachytherapy)
- ☐ Hormone therapy
- ☐ Watchful waiting (No treatment, but getting regular blood tests to check on the status of the cancer)
- ☐ They all have the same chance of side effects
- 7) If it had been up to you, which treatment would you have chosen for your partner?
- ☐ Surgery                      ☐ Radiation therapy                      ☐ Watchful waiting
- ☐ Seed implants                      ☐ Hormone therapy                      ☐ Other (please explain):

**Questions 8-12 ask about your thoughts about what your PARTNER thinks about different treatments and possible side effects. Please remember to respond without input from your partner.**

- 8) How concerned do **you think your partner** is about experiencing incontinence (which is trouble controlling his urine)?
- ☐ Extremely concerned                      ☐ Very concerned                      ☐ Somewhat concerned
- ☐ Slightly concerned                      ☐ Not at all concerned                      ☐ I don't know
- 9) How concerned do **you think your partner** is about experiencing impotence (which is inability to attain or maintain an erection)?
- ☐ Extremely concerned                      ☐ Very concerned                      ☐ Somewhat concerned
- ☐ Slightly concerned                      ☐ Not at all concerned                      ☐ I don't know
- 10) How concerned do **you think your partner** is about experiencing the risks of anesthesia (the medicine that they give to patients to put them to sleep during the surgery during which they remove the prostate)?
- ☐ Extremely concerned                      ☐ Very concerned                      ☐ Somewhat concerned
- ☐ Slightly concerned                      ☐ Not at all concerned                      ☐ I don't know
- 11) Which treatment do **you think your partner** thinks has the best chance of cure for him?
- ☐ Surgery                      ☐ Radiation therapy                      ☐ Hormone therapy
- ☐ Watchful waiting                      ☐ Seed implants                      ☐ I don't know
- ☐ They all have the same chance of cure
- 12) Which treatment do **you think your partner** thinks has the best chance of avoiding side effects?
- ☐ Surgery                      ☐ Radiation therapy                      ☐ Hormone therapy
- ☐ Watchful waiting                      ☐ Seed implants                      ☐ I don't know
- ☐ They all have the same chance of side effects

- 13) How often did you and your partner discuss his treatment options? *(please circle a number below)*

1	2	3	4	5
Never	Seldom	Now and then	Quite often	Very often

- 14) Would you have preferred to discuss your treatment options more or less? *(please circle a number below)*

1	2	3	4	5
Much less	A little less	Neither more nor less	A little more	Much more

***If you responded "never" to question 13, skip to question 17. Otherwise, continue to question 15.***

- 15) When you had these discussions about treatment options, who initiated them?

☐ Me      ☐ My partner      ☐ We both initiated some of the discussions.

- 16) How satisfied were you with those discussions? *(please circle a number below)*

1	2	3	4	5
Very dissatisfied	Somewhat dissatisfied	Neither satisfied nor dissatisfied	Somewhat satisfied	Very satisfied

- 17) How often did you and your spouse get into a disagreement or conflict over the issue of which treatment to choose? *(please circle a number below)*

1	2	3	4	5
Never	Seldom	Now and then	Quite often	Very often

**The following statements focus on the way you deal with the fact that your partner has prostate cancer. Please indicate to what extent you do or do not act in the ways described.**

	Never	Seldom	Now and then	Quite often	Very often
18) I try to discuss it with my partner openly	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
19) I ask my partner how he feels	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
20) When something bothers my partner, I try to discuss the problem	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
21) I am full of understanding towards my partner	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
22) I make my partner feel that he or she is not alone in this	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
23) I try to persuade my partner to follow the doctor's instructions	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
24) I try to hide my worries about my partner	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
25) I try to act as if nothing is the matter	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
26) I give in when my partner makes an issue of something	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
27) I just wave my partner's worries aside	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
28) I do everything to prevent my partner from thinking about his or her disease	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
29) I can't endure my partner being concerned and act as if I do not notice my partner's worries.	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
30) I take over as much of my partner's work as possible.	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>

31) How strongly did you want your opinion to be factored into your partner's treatment decision? *(Circle a number below)*

1                      2                      3                      4                      5  
Not at all              A little              Somewhat              Very              Extremely

32) How satisfied are you with the information you have about your partner's prostate cancer diagnosis and treatment options? *(Circle a number below)*

1                      2                      3                      4                      5  
Very              Somewhat              Neither satisfied              Somewhat              Very  
dissatisfied              dissatisfied              nor dissatisfied              satisfied              satisfied

**This last section asks a few questions about you.**

40) What is your age? \_\_\_\_\_ years

41) What is your race?

☐ African-American

☐ Caucasian

☐ Hispanic

☐ Asian-American

☐ Other (please specify) \_\_\_\_\_

42) What level of education have you completed? ((*Circle a number below*))

9 10 11 12

13 14 15 16

17 18 19 20 21+

high school

college

graduate school

**Thank you for your participation. Please mail the completed survey  
in the enclosed, stamped, addressed envelope.**



## **Appendix C: Physician survey**

Please fill out this questionnaire after telling your patient of his positive prostate biopsy and his treatment options.

Date \_\_\_\_/\_\_\_\_/\_\_\_\_

Patient name \_\_\_\_\_

- 1) Did you recommend a particular treatment to the patient? ☐ Yes ☐ No

*If no, skip to Question # 4*

*If yes →*

- 2) What was the recommendation (*check all that apply*)?

- ☐ Radical prostatectomy ☐ Radiation therapy ☐ Hormone therapy  
☐ Brachytherapy ☐ Watchful waiting ☐ Other (Please explain):

- 3) On a scale from 0 to 10, where 0 is not at all strong and 10 is extremely strong, how strong was your recommendation for this treatment option? (*circle one number*)

1                      2                      3                      4                      5  
Not at all              Slightly              Somewhat              Very              Extremely  
Strong                  strong                  strong                  strong                  strong

- 4) Do you think that the patient felt free to ask any questions that he had? ☐ Yes ☐ No

- 5) Did you suggest that the patient speak to a radiation oncologist? ☐ Yes ☐ No

- 6) How concerned do you think this patient is about each of the following:

**impotence**

- ☐ Extremely  
☐ Very  
☐ Somewhat  
☐ Slightly  
☐ Not at all  
☐ I don't know

**incontinence**

- ☐ Extremely  
☐ Very  
☐ Somewhat  
☐ Slightly  
☐ Not at all  
☐ I don't know

**risks of anesthesia**

- ☐ Extremely  
☐ Very  
☐ Somewhat  
☐ Slightly  
☐ Not at all  
☐ I don't know

Did you give the patient **information about each of the following** things using **numbers** (for example, "a 2% chance") or **words** (for example, "a very small chance")?

**Chance of impotence:**

- ☐ No numbers/only words ☐ Some numbers/some words  
☐ Only numbers/no words

**Chance of incontinence:**

- ☐ No numbers/only words ☐ Some numbers/some words  
☐ Only numbers/no words

**Chance of death:**

- ☐ No numbers/only words
- ☐ Only numbers/no words

☐ Some numbers/some words

**Chance of cure:**

- ☐ No numbers/only words
- ☐ Only numbers/no words

☐ Some numbers/some words

7) Which best describes how the patient's treatment decision was made?

- ☐ I made the final decision
- ☐ I made the final decision after seriously considering the patient's opinion
- ☐ The patient and I shared responsibility for the final decision.
- ☐ The patient made the final decision after seriously considering my opinion.
- ☐ The patient made the final decision on the basis of the facts he learned from me and elsewhere, without considering my opinion.
- ☐ I dont know (because the patient made the decision with another doctor, *or for some other reason*)

## Appendix D: Abstracts

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## ABSTRACT I:

### TREATMENT DECISION FACTORS IN MEN WITH NEWLY DIAGNOSED PROSTATE CANCER

Andrea D. Gurmankin, Adam Kaufman, Peter A. Ubel, James C. Coyne, S. Bruce Malkowicz, Katrina Armstrong

Prostate cancer treatment decisions can be difficult for patients because of the absence of a dominant treatment option and high-stakes, value-laden trade offs between higher survival rates and treatment side effects. How do patients weigh the many factors involved in prostate cancer treatment decisions and are these factors weighed differentially in those who choose surgery versus a nonsurgical treatment option? We investigated the importance of a series of decision factors in patients with newly diagnosed prostate cancer just after they had made their treatment decision. After obtaining written consent, surveys were mailed to consecutive patients at the Hospital of the University of Pennsylvania and the Philadelphia Veteran's Affairs Medical Center (n=233). Table 1 shows the importance of each decision factor to all subjects, and a comparison of the importance of each decision factor to those who chose surgery versus those who chose a nonsurgical treatment. More than 60% of subjects reported that longevity, feeling certain that the cancer is completely gone, impotence, and keeping my body intact were very or extremely important in their decision. Chi Square tests comparing the importance of decision factors in those who chose surgery versus those who chose nonsurgical treatments revealed that longevity, feeling certain the cancer was gone and impotence were rated as very or extremely important significantly more often in men choosing surgery ( $p < .04$  for those comparisons). Keeping one's body intact and avoiding losing identity as a man were rated as very or extremely important significantly more often in men choosing a nonsurgical treatment ( $p < .02$  for both comparisons). This study highlights several factors that influence decisions about treatment for localized prostate cancer and raises the need for additional investigation into why patients who are more concerned about impotence, which is more likely to occur from surgery than nonsurgical treatment, were more likely to choose surgery.

Table 1. Importance of decision factors

Decision Factor	% RESPONDING "VERY OR EXTREMELY IMPORTANT"		
	Chose surgery (n=97)	Chose nonsurgical treatment (n=129)	$\chi^2$ test (p value)
Longevity	95%	87%	.04
Feeling certain that cancer is completely gone	99%	84%	.0001
"Track record" of treatment	93%	86%	.11
Spouse's opinion	89%	86%	.56
Urologist's opinion	88%	86%	.73
Incontinence	80%	77%	.51
How quickly the treatment works	72%	69%	.61
Impotence	71%	53%	.007
Primary care doctor's opinion	63%	74%	.06
Keeping my body intact	56%	75%	.002
Recovery time from treatment	49%	61%	.08
Avoiding losing identity as a man	51%	66%	.02
Discomfort of the treatment	40%	51%	.10
Time it takes to get treatment	53%	47%	.43
Family member's opinion	46%	63%	.01
Opinion of friend who has or had prostate cancer	41%	58%	.01
Risks of anesthesia	31%	44%	.04
Cost of treatment	15%	35%	.001

## ABSTRACT II:

### INFORMATION-GATHERING PROCESS AND KNOWLEDGE OF TREATMENT OPTIONS IN MEN MAKING PROSTATE CANCER TREATMENT DECISIONS

Andrea D. Gurmankin, Adam Kaufman, Peter A. Ubel, James C. Coyne, S. Bruce Malkowicz, Katrina Armstrong

Prostate cancer treatment decisions can be difficult for patients because of the absence of a dominant treatment option and the high-stakes, value-laden trade offs between higher survival rates and treatment side effects. What is the process that patients go through to gather information about their treatment options in order to make this difficult decision and how well informed are patients at the end of this process? We investigated the information-gathering process and resulting knowledge of treatment options in patients with newly diagnosed prostate cancer. After obtaining written consent, surveys were mailed to consecutive patients at the Hospital of the University of Pennsylvania and the Philadelphia Veteran's Affairs Medical Center (n=233) after a treatment decision had been made. Nearly all patients report getting information about treatment options from their urologist (90%), although 39% report wishing they had received more information from the urologist. The timing of this discussion varied, occurring before biopsy results were available for 25%, during the same conversation when biopsy results were told for 27% and in a conversation after biopsy results were told for 46%. Twenty-three percent of patients reported getting a second opinion from another urologist and 73% report consulting with a radiation oncologist. Many patients also report getting information from their primary care doctor (50%), a friend/acquaintance who is a doctor (23%), prostate cancer survivors (54%), the internet (35%) and books/medical journals (57%). However, as shown in Figure 1, at the end of this information-gathering process, after patients had made their treatment decision, some patients report not having heard of some of the common treatment options for prostate cancer.

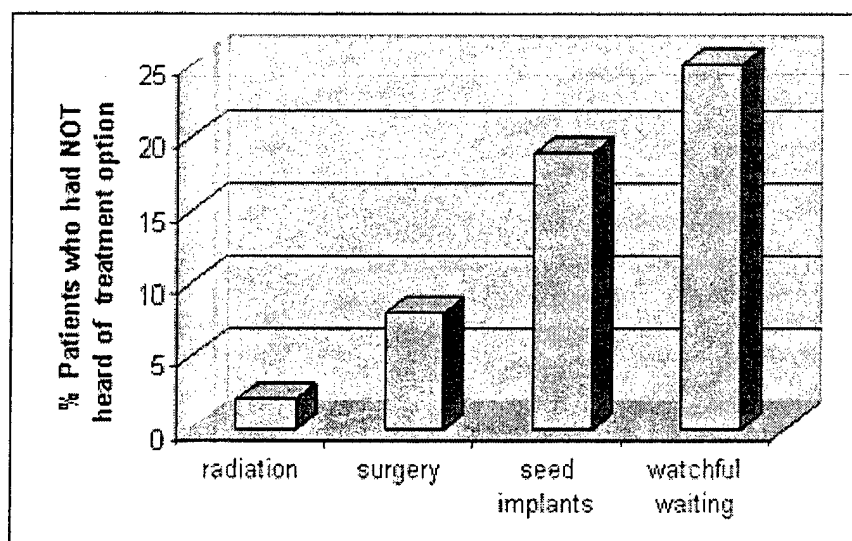


Figure 1. Patient knowledge of treatment options

\*\*This abstract has been updated to include the full dataset.

### ABSTRACT III:

## THE ROLE OF UROLOGISTS' RECOMMENDATIONS IN TREATMENT DECISIONS OF MEN WITH NEWLY DIAGNOSED PROSTATE CANCER

Andrea D. Gurmankin, Adam Kaufman, Peter A. Ubel, James C. Coyne, S. Bruce Malkowicz, Katrina Armstrong

Prostate cancer treatment decisions can be difficult for patients because of the absence of a dominant treatment option and high-stakes, value-laden trade offs between higher survival rates and treatment side effects. Physician recommendations can have a complex role in these medical decisions. On one hand, the difficulty of the decision may make patients more reliant on their physician's recommendation. On the other hand, the value-laden nature of the decision may lead patients to disregard the recommendation and to make their own treatment decision. In this study, we explored the role of the urologist's recommendation in the treatment decisions of men with newly diagnosed prostate cancer. After obtaining written consent, surveys were mailed to consecutive patients at the Hospital of the University of Pennsylvania and the Philadelphia Veteran's Affairs Medical Center (VA) (n=233) after a treatment decision had been made. The 14 urologists of the VA patients also completed a survey about their newly diagnosed prostate cancer patients. Urologists completed surveys about 184 of their patients. Eighty-three percent of patients report wanting to hear their urologist's recommendation, and 71% report receiving a recommendation, 53% of which were perceived to be very or extremely strong. Figure 1 shows the percent of patients who report receiving a recommendation for each treatment option and the percent who chose each treatment option. Fifty-seven percent of patients received a recommendation for surgery, 30% for radiation, 6% for watchful waiting, 11% for hormone therapy and 7% for seed implants. Seventy-nine percent of patients who were recommended surgery chose surgery, compared to 4% who were not recommended surgery ( $p<.0001$ ). Eighty-six percent of patients who were recommended radiation chose radiation, compared to 11% who were not recommended radiation ( $p<.0001$ ). More patients than physicians believed that the patient had made the final treatment decision (62% versus 50% respectively). Although most patients report having made the final treatment decision, our data suggest that the physicians' recommendations nevertheless played an important role in patients' treatment decisions.

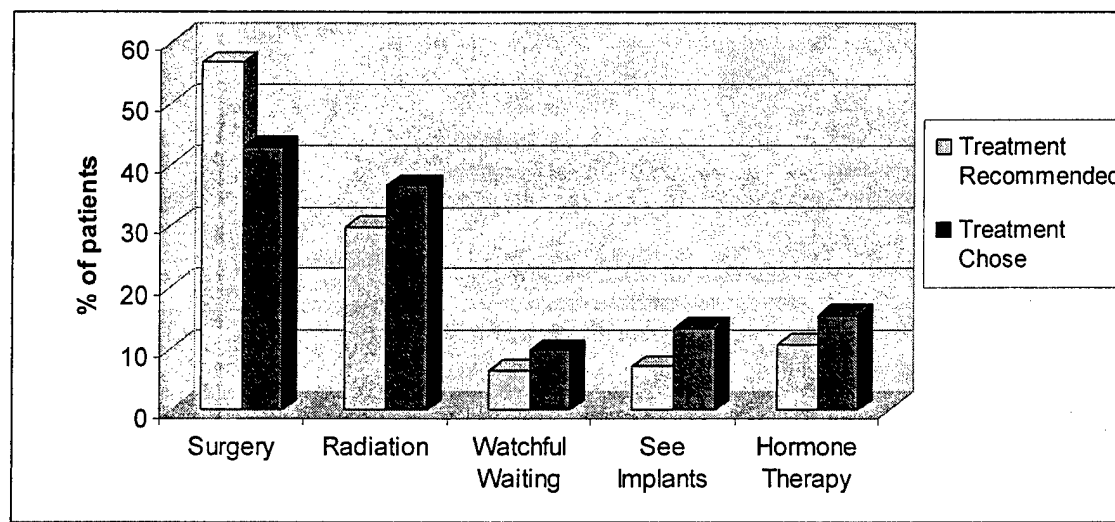


Figure 1. Percent of patients who were recommended and chose each treatment option.

\*\*This abstract has been updated to include the full dataset.



Abstract for talk at Society for Medical Decision Making (October, 2002):

The clinical reality of prostate cancer treatment decisions: is shared decision making really necessary?

Purpose: To examine urologists' role in prostate cancer patients' treatment decisions and urologists' accuracy at judging their patients' preferences and concerns. Methods: Surveys were completed by consecutive newly diagnosed prostate cancer patients (n=233) at the Hospital of the University of Pennsylvania and the Philadelphia Veteran's Affairs Medical Center (VA) after a treatment decision had been made (55 days after diagnosis, on average). VA urologists (n=14) completed a survey for each of their newly diagnosed prostate cancer patients (n=184) immediately following their appointment. Data was obtained from both the urologist and the respective patient for 68 pairs.

Table 1. Percent of patients who had not heard of, were recommended and chose each treatment (tx) option

Patients who report that they...	Surgery	Radiation therapy (XRT)	Watchful Waiting	Seed implants
had not heard of tx option	8%	2%	25%	19%
were recommended the tx option	57%	30%	7%	7%
chose the tx option	43%	37%	10%	13%

Results: Table 1 reports treatment awareness, recommendation and choice. 39% of patients wanted more information than they received and 90% wanted their urologist's recommendation. Patients who were recommended either surgery or radiation therapy (XRT) were more likely to choose that treatment than those who did not receive that recommendation (79% vs 4%,  $p < .0001$  surgery; 86% vs 12%,  $p < .0001$  XRT). Urologists underestimated their patients' desire for medical information ( $p = .0096$ ), preference for amount of information ( $p = .0005$ ) and getting the best chance of cure ( $p < .0001$ ). Although urologists rated their role in the decision as greater than patients rated their urologist on this variable, this difference did not reach statistical significance ( $p = .06$ ). Urologists and patients did not differ in their rating of the patients' role preference in their decision or the strength of the urologist's recommendation ( $p = .25$  and  $p = .77$  respectively).

Conclusion: Although urologists' recommendations appear to strongly affect treatment choice, many urologists inaccurately estimate their patients' preferences and concerns. Many patients want more information than they receive and most want their urologist's recommendation. These limitations of current clinical practice emphasize the importance of shared decision making in prostate cancer treatment

\*\*This abstract has been updated to include the full dataset.